



PO Box 3074, Lismore NSW 2480

P +61 2 6620 7570

F +61 2 6620 7270

E reception@ucrh.edu.au

www.ucrh.edu.au

Select Committee on Australia's Disaster Resilience

PO BOX 6100

Parliament House

Canberra ACT 2600

Email: disasterresilience.sen@aph.gov.au

1st May 2023

Dear Chair and Committee,

This submission to the Select Committee on Australia's Disaster Resilience is being led by Dr Jodie Bailie and Associate Professor Michelle Villeneuve, in collaboration with Dr Jo Longman. We are researchers at The University of Sydney's, University Centre for Rural Health (UCRH) (JB, JL) and Centre for Disability Research and Policy (CDRP) (JB, MV). The UCRH provides rural health education and conducts research relevant to needs of rural communities and is situated within the Northern Rivers region of NSW. The CDRP produces collaborative research that actively influences policy and practice to improve the lives of people with disability.

This submission specifically addresses the terms of reference related to:

a) current preparedness, response and recovery models, point iv) the role of Australian civil and volunteer groups, not-for-profit organisations and state-based services in preparing for and responding to and recovery from natural disasters.

Research conducted by the UCRH six months after the 2017 floods in the Northern Rivers region of NSW revealed the profound impacts and systemic neglect experienced by people with disability and their carers during and after the flooding. (1) Our study found that people with disability and carers were disproportionately impacted by the floods. They were more likely than others to:

- have their homes flooded and be evacuated
- still be displaced six months later
- experience disrupted access to food, support networks and essential services such as healthcare and social services
- continue to be distressed about the flood six months after it occurred
- be at relatively high risk of post-traumatic stress disorder six months after the flood.

Our study identified several barriers to evacuations, including inaccessible, conflicting, and confusing information, and poorly timed or incorrect warnings regarding flood-water levels and the possible need for evacuation, and communication barriers affecting access to emergency information and ability to seek assistance.

'Didn't know what evacuation meant for example, what to take, would I have to stay there, where to go... Had no idea what river levels meant.' (Person with disability, No. 154)

When people with disability wait too long it causes challenges because there are inadequate resources in the emergency sector to evacuate everyone. Respondents reported taking longer to evacuate due to a lack of transport and the extra time needed to pack and move additional equipment, as well as sensory challenges and the disruptions to their routine.

'... when we did evacuate it was late because we were worried about our children ... one who is autistic and is easily stressed when routines are disrupted'. (Carer, No. 13)

The Leave Nobody Behind research program (2, 3) led by Associate Professor Villeneuve, has gathered nationally representative data from people with disability, carers, health and social welfare organisations, and individual service providers to identify barriers for people with disability in emergency situations and mobilise cross-sector collaborative action. Findings from this research will be shared at Australia's first National forum on Disability Inclusive Disaster Risk Reduction (DIDRR) on 2 June 2023. This program will culminate in a scalable framework for cross-sector collaboration on DIDRR, providing actionable guidance. However, ongoing investment will be required to implement and evaluate the impact of the new framework on safety and well-being outcomes. It is critical that people with disability are key stakeholders in ongoing implementation at the local community level.(2, 3)

Despite the importance of preparedness to mitigate the impact on people with disabilities, there has been little attention given to the scarcity of disability data, a crucial underlying factor that precludes movement towards inclusion and ultimately addressing inequities. (1, 4, 5) Most jurisdictions have only a limited idea of how many people with disabilities live or work in flood-prone areas. Without this data, the impact of events such as floods on people with disabilities remains difficult to address and perpetuates their exclusion. (1).

Actions proposed:

1. Develop disability-inclusive responses to weather-related events, given that people with disability and carers are disproportionately impacted by floods.
2. Improve early warning systems for evacuation by making the information available and accessible to people with disability, in partnership with trusted community leaders and groups. This will mitigate the expectations on emergency services that cannot currently be met.
3. Invest in preparedness in areas where disasters are likely to occur again and where the most socially marginalised populations reside. For instance, in the Northern Rivers region of NSW, where floods are likely to occur again, prioritize resources and support to priority populations who are disproportionately affected, such as those who live in flood-prone areas and are socioeconomically disadvantaged.
4. Ensure the purposeful inclusion of people with disability and carers in both flood preparedness and recovery efforts, by involving them in community-level disaster preparedness. The vulnerability of people with disability and carers is further increased because they have not been included in community-level disaster preparedness.
5. Invest in person-centred emergency preparedness approaches, using established co-designed Australian tools such as Person-Centred Emergency Preparedness (P-CEP) (2) to assist people with disability to be involved in planning how they will respond in an emergency. P-CEP emphasises the roles of multiple stakeholders in reducing disaster risk,

rather than restricting actions to those of government and emergency services to protect people with disability and carers.

6. Improve data collection systems to identify people with disability in flood-prone areas to help address inequities and reduce disaster risk.
7. Provide longer term tailored supports to people with disability who will take longer to recover from floods.
8. Develop a national Disability Inclusive Disaster Risk Reduction (DIDRR) data framework in consultation with multiple agencies across all levels of governments, the private, non-for-profit and research sectors, and people with lived experience. This framework should provide agreed definitions, methodologies and standards on production, linkage, access, analysis, and exchange of DIDRR data, information, and knowledge.
10. Utilize community-based services that provide routine care and support as an untapped local community asset with the potential to increase safety and well-being for people with disability in emergencies. Harnessing this potential is a complex challenge but there are solutions and a path forward. These have been outlined in the Clearing a Path Report which *outlines 6 issues and 5 recommendations for action.*(6)
11. Invest in ongoing and targeted research that builds on what we have learned and investing in expansion of research in rural and regional areas.
 - a. Current and ongoing research led by Associate Professor Villeneuve is focused on the preparedness, capabilities and support needs of people with disability and carers before, during and after disasters.
 - b. Research institutions like the UCRH have a track record in community-academic partnerships who can support such programs to flourish in partnership with communities.

Concerns have been raised in 2020 by the Disability Royal Commission (7) that people with disability are overlooked or left behind during emergencies. We must ensure we hear from people with disability and carers to ensure that nobody is left behind at any stage.

If you require additional information, please get in touch with Dr Jodie Bailie on

We would be happy to speak to this research and look forward to the outcomes of your important work.

Regards

Dr Jodie Bailie

On behalf of Associate Professor Michelle Villeneuve and Dr Jo Longman

References

1. Bailie J, Matthews V, Bailie R, Villeneuve M, Longman J. [Exposure to risk and experiences of river flooding for people with disability and carers in rural Australia: a cross-sectional survey](#). BMJ Open. 2022 Aug 2;12(8):e056210
2. Villeneuve, M. (2022). Disability inclusive emergency planning: Person-centred emergency preparedness. Oxford Research Encyclopedia of Global Public Health.
3. Leave Nobody Behind <https://collaborating4inclusion.org/leave-nobody-behind/>
4. Bailie J, Fortune N, Gordon J, Madden RC, Llewellyn G. [Making everyone count: it is time to improve the visibility of people with disability in primary care](#). Med J Aust. 2022 Aug 15;217(4):173-175. doi: 10.5694/mja2.51650. Epub 2022 Jul 31.
5. Fortune N, Bailie J, Llewellyn G. [The need for improved Australian data on social determinants of health inequities](#). Med J Aust. 2022 Sep 19;217(6):325. doi: 10.5694/mja2.51698. Epub 2022 Aug 25.
6. Villeneuve, M. (2020). [Clearing a path to full inclusion of people with disability in emergency management policy and practice in Australia](#). Centre for Disability Research and Policy. The University of Sydney, NSW, 2006.

7. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. [Emergency Planning and Response](#). 2020.

Other articles published in The Conversation related to our research.

- Bailie J et al. [Floods can worsen inequality. Here are 4 ways we can ensure people with disabilities aren't left behind](#). The Conversation. Published 15 April 2021.
- Bailie J, et al. [Homeless and looking for help – why people with disability and their carers fare worse after floods](#). The Conversation. Published 15 March 2022.
- Villeneuve, M. (2021). [3 things we can do now to help people with disability prepare for disaster](#). The Conversation. Published 11 January 2021.
- Villeneuve, M. (2020). [‘Nobody checked on us’: What people with disability told us about their experiences of disasters and emergencies](#). The Conversation. Published 2 December 2020.